



## DEPARTMENT OF HEALTH AND HUMAN SERVICES

### Health Resources and Services Administration

#### Meeting of the Advisory Committee on Heritable Disorders in Newborns and Children

**AGENCY:** Health Resources and Services Administration (HRSA), Department of Health and Human Services.

**ACTION:** Notice.

**SUMMARY:** In accordance with the Federal Advisory Committee Act, this notice announces that the Advisory Committee on Heritable Disorders in Newborns and Children (ACHDNC or Committee) scheduled a public meeting. Information about ACHDNC and the agenda for this meeting can be found on the ACHDNC website at <https://www.hrsa.gov/advisory-committees/heritable-disorders/index.html>.

**DATES:** Thursday, May 4, 2023, from 9:30 AM to 3:00 PM Eastern Time and Friday, May 5, 2023, from 9:30 AM to 2:00 PM Eastern Time.

**ADDRESSES:** This meeting will be held in person with an option to join virtually. While this meeting is open to the public, advance registration is required. Please visit the ACHDNC website for information on registration: <https://www.hrsa.gov/advisory-committees/heritable-disorders/index.html> by the deadline of 12:00 PM ET on May 3, 2023. Instructions on how to access the meeting via webcast will be provided upon registration.

If you are a non-U.S. citizen who would like to attend the May meeting in-person, please contact [ACHDNC@hrsa.gov](mailto:ACHDNC@hrsa.gov) by April 12, 2023.

**FOR FURTHER INFORMATION CONTACT:** Alaina Harris, Maternal and Child Health Bureau, HRSA, 5600 Fishers Lane, Room 18W66, Rockville, Maryland 20857; 301-443-0721; or [ACHDNC@hrsa.gov](mailto:ACHDNC@hrsa.gov).

**SUPPLEMENTARY INFORMATION:** ACHDNC provides advice and recommendations to the Secretary of Health and Human Services (Secretary) on the development of newborn

screening activities, technologies, policies, guidelines, and programs for effectively reducing morbidity and mortality in newborns and children having, or at risk for, heritable disorders. ACHDNC reviews and reports regularly on newborn and childhood screening practices, recommends improvements in the national newborn and childhood screening programs, and fulfills requirements stated in the authorizing legislation. In addition, ACHDNC's recommendations regarding inclusion of additional conditions for screening on the Recommended Uniform Screening Panel, following adoption by the Secretary, are evidence-informed preventive health services provided for in the comprehensive guidelines supported by HRSA pursuant to section 2713 of the Public Health Service Act (42 U.S.C. 300gg-13). Under this provision, non-grandfathered group health plans and health insurance issuers offering non-grandfathered group or individual health insurance are required to provide insurance coverage without cost-sharing (a co-payment, co-insurance, or deductible) for preventive services for plan years (i.e., policy years) beginning on or after the date that is 1 year from the Secretary's adoption of the condition for screening.

During the May 4-5, 2023, meeting, ACHDNC will hear from experts in the fields of public health, medicine, heritable disorders, rare disorders, and newborn screening. Agenda items may include the following topics:

- 1) ACHDNC committee processes including prioritization and capacity of reviewing initial nominations;
- 2) Criteria for pilot studies related to newborn screening;
- 3) Center for Disease Control and Prevention's Enhancing Data Driven Disease Detection in Newborns (ED3N) Project; and
- 4) ACHDNC Decision Matrix.

Agenda items are subject to change as priorities dictate. However, no votes will be held at this meeting to recommend including additional conditions for screening to the Recommended

Uniform Screening Panel. Information about ACHDNC, including a roster of members and past meeting summaries, is also available on ACHDNC's website.

Members of the public also will have the opportunity to provide comments on any or all of the above agenda items. Public participants may request to provide general oral comments and may submit written statements in advance of the scheduled meeting. Oral comments will be honored in the order they are requested and may be limited as time allows. Members of the public registered to provide oral public comments on all other newborn screening related topics are tentatively scheduled to provide their statements on Friday, May 5, 2023. Requests to provide a written statement or make oral comments to the ACHDNC must be submitted via the registration website by 12:00 PM ET on Wednesday, April 19, 2023. Written comments will be shared with the Committee, so that they have an opportunity to consider them prior to the meeting.

Individuals who need special assistance or another reasonable accommodation should notify Alaina Harris at the address and phone number listed above at least 10 business days prior to the meeting.

Since this meeting occurs in a federal government building, attendees must go through a security check to enter the building. Non-U.S. citizen attendees must notify HRSA of their planned attendance at least 15 business days prior to the meeting in order to facilitate their entry into the building. All attendees are required to present government-issued identification prior to entry.

**Maria G. Button,**

*Director, Executive Secretariat.*

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